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SPECIAL REPORT

Stacking the deck: *Ottawa meeting on controversial illness is loaded with advocates, c*

Stories by PAUL BENEDETTI
The Spectator

Most people call it 20th Century Disease.

The Canadian Society for Allergy and Clinical Immunology says it doesn't exist.

Ditto four major North American medical associations and committees.

The vast majority of scientists and physicians agree the patients are sick, but not from sensitivity to chemicals.

They don't think 20th Century Disease, which is also known by several names including Multiple Chemical Sensitivity (MCS), is a real disease at all.

So why is the overwhelming majority of the nine speakers invited by the federal government to a meeting on Multiple Chemical Sensitivity proponents of the disease?

Why are at least three of these people clinical ecologists — doctors who practice "environmental medicine" using unproven and largely unaccepted diagnosis and treatment methods?

And why are at least four of these panel members people who believe they have MCS themselves, including one doctor who has become a spokesman for the Canadian environmental sensitivity patient lobby group?

The answers are important because the implications are huge.

Health and Welfare Canada, which has organized the Dec. 7 meeting, ... tive is to produce a working defi... and "a background document ... titioners in the management of ... present with these symptoms."

Critics say any errant prod... biased panel could influence ... government policy and fosh...

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WHO IS ON THE PANEL

THE PANEL invited to speak at the federal meeting on Multiple Chemical Sensitivity consists of:

Dr. Iris Bell, author of Clinical Ecology: A New Medical Approach To Environmental Illness. She has been an associate fellow of the Society for Clinical Ecology since 1974 and a clinical member since 1980.

Dr. Gerald Ross is the director of the Environmental Medicine Clinic at Victoria General Hospital in Halifax. He believes he has MCS and wrote about his experiences and the syndrome in a three-part Medical Post series in 1989. He now conducts clinical ecology research in Texas.

Dr. Nicholas Ashford is an associate professor of technology and policy at the Massachusetts Institute of Technology.

Dr. Claudia Miller is an assistant professor of allergy and immunology at the University of Texas Health Centre in San Antonio. Along with Dr. Ashford, she is author of Chemical Exposures: Low Levels And High Stakes, a book supportive of the diagnosis of MSC.

Dr. Lynn Marshall, an Ottawa doctor who now works in Toronto, believes she suffers from the syndrome and treats MCS patients. She is a member of the American Academy of Environmental Medicine, an American association of physicians practising "environmental medicine."

Dr. Roy Fox, the former director of the Centre for Health Care of the Elderly at Camp Hill Medical Centre in Nova Scotia. Now retired after being diagnosed with environmental disease, he has become a spokesman for the Allergy and Environmental Health Association, a group representing MCS patient interests.

Dr. Eric Nisbett-Brown, clinical immunologist and head of immunology at Toronto General Hospital. He does research in the field and works with MCS patients, and while skeptical about many techniques used by clinical ecologists, he believes environmental illness "almost certainly exists."

Dr. Nancy Fiedler, clinical psychologist and assistant professor in the Environmental and Occupational Health Sciences Institute, Robert Wood Johnson Medical School in New Jersey. Currently researching MSC and has presented papers to the American National Research Council. She is not an MCS advocate, and says the panel is unbalanced.

Dr. Susan Abbey, staff psychiatrist at Toronto General, assistant professor of medicine, University of Toronto, and board member of the Canadian Psychiatric Association. She has published research on the relationship of chronic fatigue and psychiatric disorders. She feels strongly that the meeting should not be a forum for MCS advocates.

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health care system being indundated with claims for compensation, disability and treatment by MCS patients.

And that, say doctors, could cost health insurance, workers compensation boards, unemployment insurance and disability plans many millions of dollars.

But advocates across North America are fighting for recognition of the disease and coverage under government and private insurance plans. In Ontario, OHIP will not cover MCS treatments and Workers Compensation does not recognize it as a compensatory disease.

Major medical bodies such as the Canadian Psychiatric Association and the Canadian Society of Allergy and Immunology do not support the theory, practice and treatments of clinical ecology. This month a Nova Scotia government-appointed committee on environmental illness announced it could "find no evidence to support" the existence of the disease.

Yet the panel assembled by Health and Welfare includes six advocates who practice clinical ecology or have published articles or books in support of the MCS argument.

"It surprises me that the federal government would sponsor such a biased, one-sided panel," said Dr. Kempton Hayes, chairman of a Nova Scotia provincial government committee which examined Environmental Hypersensitivity.

Other doctors agree.

"There appears to be a political agenda to have a program of people who are in support of the diagnosis," says Dr. Susan Abbey, a Toronto psychiatrist who was invited to the meeting. "I think the government should be providing leadership and convene a meeting with people who have open minds."

Dr. Nancy Fiedler, a New Jersey clinical psychologist who is speaking at the meeting, said she also feels the panel is unbalanced. "They are mostly proponents," she said.

Dr. Abbey wrote to the conference organizers to express her concerns.

But Gwen Gowanlock, director of the mental health division and organizer of the one-day meeting, defends the panel's composition. "We feel we invited people who could add something to the subject matter... People with an interest in it or some expertise in the area," she said.

SHE SAID THE MEETING is being held "to see if there are any implications, recommendations, things that can come out of that for action on a number of fronts — government, non-government, scientific."

Ms Gowanlock would not describe the process by which her department chose the panelists, other than to say "it was an internal process. We had a meeting and we proceeded with inviting some individuals and that is all."

The conference, the morning portion of the program is by invitation only, but the scheduled afternoon workshops are closed except to panel participants.

Dr. Felix Li, who is co-organizer of the meeting, also defended the panel selection but said that, because of questions raised by The Spectator, he would be reviewing the situation.

Stacking the deck

Protecting MCS patients from the environment could push health-care costs sky-high.

Spectator Graphic, Mike Baldwin

"Our intent was to invite speakers with different viewpoints... hopefully the spectrum of speakers will provide a balanced view on the subject," said Dr. Li, head of the Laboratory for Disease Control, health protection branch.

Dr. Eric Nisbett-Brown, head of immunology at Toronto General and an invited speaker, feels the panel could provide an "important and exciting" meeting.

"I'm aware that it is a somewhat weighted panel, but I don't have a problem with it because I do see that there are indeed people with different viewpoints there," he said.

But doctors and representatives of key medical bodies who contacted Ms Gowanlock about what they saw as an imbalance of views say they were given the brush-off.

Dr. Bill Moote, president of the Canadian Society of Allergy and Clinical Immunology, said his association will have someone attend the meeting. "We don't have any option other than going and being a thorn in their side, and refusing to let silliness be stated as fact... They really don't have any business setting up a workshop with that much bias."

Dr. Moote said the Society was invited to attend the meeting but not to provide a speaker. He asked the organizers to be allowed to present a 10-minute talk on the immunological implications of MCS.

The answer was no, but Dr. Moote was asked to take part in the scheduled afternoon sessions from which the final report will emerge. "This should not come out as a clinical ecology mouthpiece," he said.

Susan Daglish, executive director of the Allergy Information Association — a non-profit national organization that helps people with allergies — says she is concerned about the "one-sided" nature of the conference.

"Why isn't there someone from the mainstream allergy side?," she said. "I wasn't sure I was going to attend because the program was lopsided."

DR. ABBEY SAID THAT when she first received a list of panel members, she was surprised by who was invited and who was not.

The official title of the conference is: Multiple Chemical Sensitivities And Their Relevance To Psychiatric Disorders. But, says Dr. Abbey, the leading Canadian researcher in the field — Dr. Donna Stewart of Toronto, who published an influential paper called A Psychiatric Assessment Of Patients With 20th Century Disease — was not invited to speak.

"She's recognized throughout North America for her work," said Dr. Abbey. "There's something very odd going on when the leading Canadian psychiatrist in the area is not invited."

Dr. Abbey, who agrees with the mainstream psychiatric view of MCS, was invited to speak about chronic fatigue, not MCS. And while other speakers were given 25 minutes for their presentations, she was allotted only 20.

Ms Gowanlock said the shorter allotment was inadvertent. "It wasn't an intentional thing."

Dr. Abbey expressed her concerns to Ms Gowanlock in a detailed and strongly-worded letter this summer. She wrote:

"I applaud the interest of Health and Welfare Canada in conducting a workshop on the relevance of psychiatric disorders to this entity. However, my hope would be that this would involve a serious attempt to explore the scientific data available and to disseminate the proven knowledge about the syndrome... In reviewing the program as it now stands there have been serious deficits.

"It appears the primary criterion for participation is advocacy, with many of the professionals involved themselves having the syndrome. If there is a desire for this to be more than a political forum for advocacy, I think it is important to include more speakers... who have carefully studied the area in peer-reviewed publications."

Dr. Abbey then recommended a list of experts in the field. "I realize these names may be problematic to the advocacy groups because these individuals have critically evaluated the syndrome," she wrote in the letter. "Nonetheless, patients and medical professionals need sound advice based on scientific work and these professionals have made important contributions to the field."

Dr. Fiedler concurs that other experts should have been invited, and that some such as Dr. Stewart, were conspicuous by their absence.

Ms Gowanlock took about two months to respond to Dr. Abbey's letter. Her answer was that the panel "had been chosen on the basis of people recommended to us" and that budgetary constraints prevented the addition of any new speakers.

In an interview, Ms Gowanlock would not comment on the letter, but said of Dr. Abbey's recommendations: "We didn't invite them, and it's quite possible they didn't figure into the mix because we weren't aware of their work. It certainly wasn't an oversight on purpose. It may be that there are other meetings to be held."

She noted that the "whole front" could not be covered in one meeting. "We went with what we thought was a balanced group... for a beginning meeting. If we excluded people it wasn't an intentional thing."

Still, many health professionals are concerned that the meeting and its report could affect future health-care policy.

A WORKING PAPER that supports a diagnosis of environmental hypersensitivity could greatly affect patients and care costs, says Dr. Abbey. "It has enormous implications at a time when there are so many cost considerations," she added.

Dr. Herman Staudenmayer agrees. A Colorado-based scientist who has done extensive research into MCS and published numerous papers on the subject, he says patient advocacy groups and clinical ecologists are lobbying hard in the U.S. and Canada to have the disease recognized. "They're desperately trying to get a government agency to legitimize their argument. Such a move could be an economic disaster," he said. "You are tying into sick building syndrome, multiple chemical sensitivity, and the next thing, elec-

Ottawa meeting on controversial illness is loaded with advocates, critics say, and the stakes could be very high

tro-magnetic contamination. If these become legitimized, you'll see compensation claims that will bankrupt the insurance industry."

Dr. Staudenmayer said anything coming out of the Health and Welfare meeting "is absolute nonsense. The question I would ask is how the hell did this group come together."

Some lobby groups, such as the Allergy and Environmental Health Association of Canada, have called for all patients to be screened for environmental hypersensitivity before any psychiatric examination is considered.

All doctors agree that patients reporting MCS should be treated with respect and compassion, but say acceptance of their diagnosis may not help them recover. Studies by American and Canadian researchers have shown that the majority of patients do not improve with clinical ecology treatment, and many get worse.

"My concern is that people with treatable medical and psychiatric conditions might not receive the treatment they need," said Dr. Abbey.

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Spectrum

Syndrome is known by many names

Multiple Chemical Sensitivity is a strange and controversial phenomenon,—

a title given to a large number of symptoms some people believe is caused by low-level exposure to foods, and chemicals in the environment.

It is known by many names — 20th Century Disease, Environmental Hypersensitivity, Environmental Illness or Total Allergy Syndrome.

Practitioners of "environmental medicine," called clinical ecologists, believe that the exposure sensitizes certain individuals, causing them to react or become allergic to virtually everything around them.

Common irritants mentioned are pollution, perfumes, pesticides, exhaust fumes, natural gas, foods and food additives, and synthetic products found in clothes, carpets, building products and many other items.

Though there is no precise description of the disorder, it can encompass virtually an unlimited array of symptoms including: fatigue, depression, headache, irritability, anxiety, mood swings, memory lapses, poor concentration, confusion, nausea, palpitations, constipation, muscle and joint pain, vaginal burning, all of which can range from mild intermittent discomfort to total disability.

And though the patients feel terrible, they exhibit no objective physical findings or abnormal laboratory results.

In other words, nothing appears to be physically wrong with them.

In the worst cases, sufferers become totally incapable of living in the modern world, perceiving everything around them as allergy-causing and possibly life-threatening. These people are undoubtedly sick.

The debate surrounds the question: what is making them ill and how should they be treated?

Clinical Ecologists and MCS sufferers believe that a variety of treatments — including restrictive diets, isolation, avoidance of allergy triggers, and even refitting their homes to remove all allergy-causing substances — are effective and should be paid for by employers and health insurance systems.

Though the number of people suffering from MCS is unknown, advocates here and in the United States have been high-profile and vocal.

Mainstream scientists and doctors say that though the idea of environmental disease and the practice of clincial ecology have been around for decades, the theory, diagnosis and treatment methods are unproven, unsubstantiated and unacceptable.

Dr. Jerry Dolovich, an allergy specialist at McMaster University, says that there is really only one issue: "That the outcomes or conclusions should be based on a satisfactory quality of evidence. All the rest is irrelevant. Is there a quality of evidence in tests and treatments?," he asked. "Absolutely not."

Dr. Kempton Hayes, chairman of a Nova Scotia committee that studied MCS, agrees. "Clinical ecologists may be right. But they've been at this for 30 years... and the literature we've seen, which is their version of scientific proof, just doesn't hold water. It was really terrible science."

While the media often portrays the controversy as a turf war among scientists in which one expert disagrees with another, the reality is that clinical ecologists have failed to make their case in the scientific forum.

The vast majority of doctors and scientists rejects the diagnosis and the treatment methods of environmental illness.

Position statements by the American Academy of Allergy and Immunology, the California Medical Association Scientific Board Task Force, the American College of Physicians, the Canadian Psychiatric Association, and the Canadian Society of Allergists and Clinical Immunologists conclude there is not sufficient evidence to support the notion that chemical or food sensitivity produces the symptoms clustered under the title Environmental Sensitivity.

They also state that the practice of Clinical Ecology is not a valid medical discipline and that its methods have not been proven effective.

Many researchers say controlled studies of MCS sufferers point to psychiatric disorders such as clinical depression, not environmental factors, as the source of the patients' problems.

Chief of Immunology for St. Michael's Hospital in Toronto, Dr. Arthur Leznoff, says there is no question MCS patients are suffering from something. "The question is whether it's a disease," he said.